DOCUMENT RESUME

ED 284 410 EC 200 228

AUTHOR Gardner, James F.; Markowitz, Ricka Keeney
TITLE Maryland Family Support Services Consortium. Final Report.
SPONS AGENCY Maryland State Planning Council on Developmental Disabilities, Baltimore.
PUB DATE 86
NOTE 61p.
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Agency Cooperation; Assistive Devices (for Disabled); Community Services; Consortia; *Delivery Systems; Demonstration Programs; *Developmental Disabilities; *Family Programs; *Normalization (Handicapped); Public Policy; Respite Care; Shared Resources and Services; State Programs
IDENTIFIERS *Maryland

ABSTRACT

The Maryland Family Support Services Consortium is a 3-year demonstration project which developed unique family support models at five sites serving the needs of families with a developmentally disabled child (ages birth to 21). Caseworkers provided direct intensive services to 224 families over the 3-year period, including counseling, liaison and monitoring, and attendance at educational planning meetings. Data collected for each project site included service recipients, services provided, and their estimated cost. Among 26 types of services offered, the most frequently purchased were medical equipment and supplies, adaptive equipment, transportation, and respite care. Two issues affecting public policy were identified: (1) child care services for the developmentally disabled are either nonexistent or difficult to obtain; and (2) an increase in funding for family support services is necessary if such services are going to become a realistic alternative to residential programs. A fact sheet and four vignettes are appended. (JW)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED284410

Final Report of the

Maryland Family Support Services Consortium

Submitted to:

The Maryland State Planning

Council on Developmental Disabilities

James F. Gardner, Ph.D.

Project Director

Ricka Keeney Markowitz, Sc.D.

Project Coordinator

BEST COPY AVAILABLE

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Ricka Keeney Markowitz
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC200328

TABLE OF CONTENTS

		Page(s)
Executive Summary		1
Chapter One	ORGANIZATIONAL OVERVIEW	6
Chapter Two	FAMILY AND CHILD CHARACTERISTICS	9
Chapter Three	STRESS AND PROGRAM EVALUATION	25
Chapter Four	ANALYSIS OF SERVICES	35
Chapter Five	SUMMARY AND CONCLUSIONS	45
Chapter Six	RECOMMENDATIONS	48
Appendices		
Appendix A	FACT SHEET	
Appendix B	VIGNETTES OF PROGRAM FAMILIES	

EXECUTIVE SUMMARY

The 1970's and 1980's can be characterized as a transition period in the orientation of service provision to children with a developmental disability. The shift in orientation from a child focus to a family focus finally acknowledged the reciprocal importance of relationships within the home environment and the family members to the habilitation of a child with a developmental disability. Prior to this time, the focus of service providers was on the child only. This left families to chose to either care for their child at home with no outside assistance or to place their child outside the home. These options provided the family with a solution that benefited neither themselves nor their child.

The shift to a family focus was mirrored by a shift in family oriented service provision. The most significant provision model to emerge were the Family Support Services programs. These programs were unique in that they provided needed services to a family to maintain their child within their homes. By the mid 1980's every state except Oklahoma had a program providing inhome support to families. These programs vary in number of recipients, services offered, and eligibility criteria.

The Maryland State Planning Council on Developmental Disabilities was the driving force in the development of Family Support Services in Maryland. As an outgrowth of a Long Range Planning Study conducted in 1982 the Council adopted family support services as its major focus. As a result, in 1983, funding support was given to five sites forming a Consortium to develop family support models that would be responsive to needs of families with a child with a disability in Maryland. Legislation passed in 1984, the project's first year, established an ongoing program to be administered by the Developmental Disabilities Administration (DDA) in July 1986, following a period where administrative control was shared by the Council and DDA.

The Consortium sites, unified by standard eligibility criteria and program documentation, developed administrative structures that maximized existing services and reflected the unique needs of the families they served.

The specific objectives of this project were to:

1) identify the services needed by eligible families and demonstrate various approaches to providing family support services;
2) document the changes experienced by families as a result of participation in the project;
3) determine the predictive cost data for services by maintaining cost records of agency tasks and family services;
4) develop eligibility criteria, program standards and payment structure based on the experience of the five Consortium sites; and
5) reduce the need for out-of-home residential placement along targeted children and enable them to reside in the least restrictive environment.

Data submitted by each project site has provided the opportunity to document who received services, the services provided, and estimate the cost of services provided. Over the project period the data collected has been valuable to help identify trends in service provision over time. Important outcomes of the data and resulting policy recommendations are outlined below.

Family Characteristics

Characteristics of the families and children with a developmental disability did not change significantly over the project period.

- o In each year the families were very isolated as defined by their lack of sources of support.
- o No one group of individuals can be identified from the data collection who appear to be more at risk for consortium services.

Services are needed by families regardless of race, income, education or marital status.

- o Eighty percent of the families were not members of an advocacy or parent group prior to receiving services through the Consortium.
- o The drain of a child with a developmental disability appears to significantly impact on the income potential of these families. Sixty-two percent (62%) of all families had an annual income of less than $15,000 compared to Census figures showing only 20% of the families in the Maryland general population had annual incomes of less than $15,000.

Services Offered

The Maryland Consortium offered a wide range of services. The services provided reflect the unique needs of each family.

- o This project is highly personnel intensive. Caseworkers in each site provide intensive services directly to the families including counseling, liaison and monitoring and attendance at educational planning meetings.
- o Twenty-six unique types of services have been provided by the Consortium. The most frequently purchased services include respite care, purchase of medical equipment and supplies, purchase of adaptive equipment, and transportation

Services Outcomes

A total of 224 families received services through the Consortium in its three year pilot period. In Year One 101 families received services. In the remaining two years nearly equal numbers of new families received services (63 and 60 respectively).

- o No site in the Consortium maintained a waiting list of families referred for program services in any project year. The ability of

the Consortium to serve all eligible families referred appears to be the result of the belief held by site coordinators, that a waiting list is not appropriate for this "at-risk" group. Therefore innovative arrangements have been made to use existing services more effectively.

- o While families are highly stressed, the data suggests that parents perceive their role to be less stressful as a result of services received over a two year period and this trend is stabilized in families receiving services for three years.
- o The average cost of provision of services and project administration to a family has remained fairly stable in Years Two and Three (1,200.00, 1,273.42 respectively). This represents a dramatic decrease from the cost of $2,000.00 estimated per family in Year One.
- o Ten percent (10%) of the children were placed outside their homes. Reasons for placement included, physical safety of the child, poor physical health of the caregiver and the child's disruptive behavior.

Policy Implications

The Maryland Family Support Services Consortium has identified two issues that impact on public policy and the future of Family Support Services in Maryland.

- o Availability of child care services, defined as respite care, day care/preschool, and before and after school programs, for this population are extremely difficult to obtain or are non-existent in the community. The Consortium was able to provide child care services to only one half of the families requesting this service when they entered the project. The reason for this is that the services are not available even when the resources to fund the service exist.

- The fiscal resources committed to Family Support Services have not increased beyond the $220,000 that supported the Consortium in Year One of the demonstration project. If family support services are intended as an alternative to DDA residential programs it must be funded as such.

Chapter One

ORGANIZATIONAL OVERVIEW

The Maryland Family Support Services Consortium began as a three year demonstration project funded by the Maryland State Planning Council on Developmental Disabilities. The Consortium, which originated in July 1983 represented a unique approach to service delivery for families with a child with a developmental disability. This model of support to families was also tested in several other states across the nation. The Maryland Consortium had two advantages in its organization that set it apart from other statewide programs. First, it combined the service delivery component with a uniform data collection component to clearly evaluate and monitor the effect of the program. Second, the organizational structure of each site reflected the special needs of the local residents.

The Consortium operates in five (5) sites within the state of Maryland. These sites are the Association of Retarded Citizens (ARC) in Calvert County, the Association for Retarded Citizens in Frederick County, the Jewish Social Services Agency in Montgomery County and the Montgomery County Association for Retarded Citizens, the Epilepsy Association on the Eastern Shore, and the Kennedy Institute in Baltimore. These five project sites serve 13 counties within the State of Maryland representing urban and rural areas. Figure One identifies the counties served by the Consortium project. The organizational structure of each site varied. The Epilepsy Association on the Eastern Shore, composed of nine (9) counties, utilized the existing case management system as the focal point to offer services to eligible families. The ARC in Calvert County, a rural county in Southern Maryland, organized their service provision by utilizing a trained parent coordinator. The parent was herself the parent of a child with a developmental disability. The ARC in Frederick County, a rural county in Western Maryland, provided services to families through a

service coordinator. This program model was similar to the Kennedy Institute's program in Baltimore City, a large metropolitan area, in its use of the service coordination model. The program in Montgomery County, a metropolitan area near Washington, D.C. was operated jointly by two non-profit agencies utilizing a social worker with support from a nurse and physical therapist.

The two main eligibility criteria established in Year One were followed carefully throughout the project's three years. The major criteria for eligibility focused on the at-risk status of families with a child with a developmental disability. The families had to be at risk of placing their child outside the home. This criteria was evaluated using two checklists. The first form was taken from Golay's checklist for developmental disabilities. The second form was developed by the site coordinators and the Project Advisory Board. These forms identified the chronicity of the disability and the need for out of home placement as judged by previous or current placement, and/or the parent, or professional request for out of home placement of the child. The second criteria limited services to a child with a developmental disability who was younger than 22 years of age. Families were eligible for services through the Consortium regardless of the income. However, families were asked to contribute to the cost of services based on a sliding fee scale. The Maryland respite care sliding scale was used to define family responsibilities for services provided.

Families were referred from a variety of sources. The majority of referrals came from internal agency sources, or school systems. No site maintained a waiting list for referrals during the project period. Families evaluated to meet the eligibility criteria were admitted into the program. The fact that no waiting list was maintained reflects the belief by project staff that families eligible for services through this program do not benefit

by placement on a waiting list. Their need for service was so immediate and critical that a delay in services could mean the unnecessary placement of a child outside the home. In addition each site maintained close supervision of their service monies and were able to quickly evaluate their capacity to provide the needed services. The best alternative resource was sought if services could not be provided through the Consortium. Many strong working relationships were formed with existing providers in the community who could assist in meeting the service needs of families. Thus with the Consortium funds, families benefited from these relationships that made the best possible use of existing services.

Chapter Two

FAMILY AND CHILD CHARACTERISTICS

This section addresses the characteristics of families and children receiving services through the Consortium. In addition to the description of recipient characteristics the analysis in this section identifies significant changes over the project period in the population receiving services and evaluates trends in the data.

By the end of Year Three (June 30, 1986) the Consortium project had provided services to 224 families. The total number of families who had received services per site ranged from 25 to 82 families (Table One).

STATE WIDE COMPARISONS

Comparisons were made between families receiving Consortium support and all families in Maryland and families in counties with a Consortium site. The purpose of these comparisons was to better understand how representative families in the Consortium were within their counties and within the state. This analysis has strong implications for assessing the statewide need for family support services and for better defining the at risk population.

Four characteristics were selected for comparison in this analysis; race, education, family income, and age of child. There is little difference between Consortium families and the total population in the state or selected counties as related to race (Table Two). This means that no one racial group has been seen to be at higher risk for Consortium services on a project wide basis.

The families in the Consortium, as characterized by the education of the primary caregiver, tend to be slightly better educated than the comparison groups of Maryland residents.

Table One

FAMILIES SERVED THROUGH THE CONSORTIUM

BY SITE

FINAL REPORT

Project Site	Years One & Two Number of Families	Families Served in Year Three	Cumulative Total Number of Families
Calvert County	29	16	44
Eastern Shore	62	38	82
Frederick County	20	16	25
Baltimore City	22	24	37
Montgomery County	31	23	36
TOTAL	164	117	224

Table Two

COMPARISON OF CONSORTIUM RECIPIENTS TO THE
TOTAL MARYLAND POPULATION AND
TOTAL POPULATION IN CONSORTIUM COUNTIES
ON SELECTED CHARACTERISTICS

	Maryland	Consortium Counties	Consortium Project
Race*			
White	75%	67%	66%
Black, Other	25%	33%	34%
High School Graduate*	62%	65%	70%
Family Income*			
$5,000	6%	8%	14%
5,000-14,999	22%	25%	48%
15,000-24,999	14%	25%	19%
25,000	59%	42%	19%
Age of Children+			
<1	4%	5%	10%
1-4	18%	18%	18%
5-17	77%	76%	72%

* Maryland Statistical Abstract 1986-1987

\+ U.S. Department of Commerce, Bureau of the Census, General Population Characteristics, Final Report 1980, PC80-1-B22, Maryland.

The distribution of family income is somewhat suprising given the high percentage of education and comparable racial distribution. Over sixty percent (62%) of the Consortium families earn less than $15,000 compared to 28% and 33% of the total population in Consortium counties, and the total state population respectively. It appears that the presence of the child with a developmental disability and more specifically their at risk status may lead to a financial drain on families.

When ages of the children served by the Consortium were compared to the total state population of children and the total population in Consortium counties, there are striking differences. Infants (< 1 year of age) are more frequently represented in the Consortium population than in the general population for the state or counties served by a Consortium site the two populations used as reference. There is no difference in the presence of children ages 1-4 served by the Consortium. The older children 5-17, are only slightly less represented by the population served by the Consortium. These comparisons help identify whether the Consortium services were needed by specific age groups of children more frequently. It appears that children less than 1 year of age are at an increased risk for Consortium services. This is especially critical when the criteria for acceptance in the program is the assessed or expressed risk of out of home placement of their child. Interpretation of this finding from the data available is not possible. It it not known if the younger children are at increased risk over their adolescent counterparts, and if so why. These are important questions that need to be addressed.

Family Characteristics

The sociodemographic characteristics of the families served by the Consortium have remained remarkably stable over the study period (Table Three). The families tend to be mainly two parent families. Eighty percent

Table Three

COMPARISON OF FAMILY CHARACTERISTICS

BETWEEN THE THREE PROJECT YEARS

FINAL REPORT

Family Characteristics	Year One	Year Two	Year Three
Marital Status			
Married	70%	69%	68%
Single	10%	11%	11%
Other	19%	20%	21%
Education			
< High School Graduate	31%	30%	30%
High School Graduate	35%	39%	39%
Post High School Graduate	34%	31%	31%
Members of Support or Advocacy Group			
Yes	23%	20%	20%
No	77%	80%	80%
No Prior Services	75%	82%	89%
Income			
< $5,000	28%	21%	14%
$5,000 - 15,000	28%	41%	48%
$15,000 - 25,000	13%	26%	19%
$25,000 +	34%	22%	19%

(80%) have 2 or more adults. The average family in the Consortium has two children, with a range of 1 to 6 children per family.

There has been no appreciable change in the education of the primary caregivers over the study. The majority of caregivers (70%) have a high school education or greater. There are nearly equal numbers of caregivers who have less than high school diploma (30%), and those who have some college education or are college graduates (31%). More than one third of the primary caregivers are employed full or part time. Recent Labor Force statistics indicate that nearly 50% of the women with children under 18 are employed. Coupled with their education attainment it is surprising that their employment rate of 20% is significantly less than for all women.

Income of the families cover a wide range with nearly equal numbers of families at the two extremes of the income less than $5,000, and over $25,000 (14% and 19% respectively). The majority of families (62%) have incomes of less than $15,000. Within this large group the majority of families earn between $5,001 and $14,999 annually.

It is very important to understand that the need for services exists in all income levels. Family income can not serve as the sole indicator of need for services. It appears from these results that the presence of a child with developmental disability and the assessed at risk status of the family are characterized by a preponderance of low incomes and low maternal employment especially when there exists a strong potential for employment as evidenced by the education attainment of the primary caregiver.

Data from two national surveys have reported that the impact of a child with a developmental disability decreases the probability the mother will work outside the home (Salkever). One survey identified the most significantly impacted as low-income, white, two parent families. The second survey found that mothers of a child with a developmental disability whose handicap

interfered with school attendance or whose mobility was limited were significantly less likely to be employed. These findings provide valuable support for the impact of the loss in economic opportunity described by results of the Consortium project. Families participating in the Consortium indeed can be characterized as having a child whose disability effects school attendance and/or has limited mobility. These factors point up the dilema these families face, the ability of the caregiver to seek employment is out weighed by the care needs of the child.

Insurance coverage available for families at entry into the program was identified. Nearly equal numbers of families had third party insurance coverage as were eligible for Medicaid (48%, 45% respectively). Seven percent (13 families) had no insurance coverage at entry into this program. Families also qualified for other public assistance, 41% of these families received SSI, food stamps or other public sponsored assistance.

When the amount of support or assistance provided by household members, relatives, neighbors or agencies was assessed, results characterize the isolation of these families. They tend to have very little support (assistance with the care of their child) available from sources outside of household members (relatives or friends). Less than 11% report frequent assistance from friends, relatives or agencies (Table Four). A major finding in the description of these families is that the vast majority (80%) are not members of a parent or support group nor were they receiving services when they entered the Consortium.

Closer examination of group membership indicates that parents of a child with a diagosis of spina bifida, Down's syndrome or Muscular Dystrophy tend to be members of groups. This could be due to the outreach of these diagnosis specific groups. Families indicated that the caseworker was very important to them in that they were someone the family could depend on. Therefore the

Table Four

SOURCES OF SOCIAL SUPPORT AVAILABLE

TO FAMILIES

FINAL REPORT

Support to Cargiver	None	Occasional	Frequent
From Household members	24%	34%	42%
From Friends	60%	35%	5%
From Relatives	52%	37%	11%
From Agency	60%	37%	3%

caseworker provided a source of valuable support to the family after they entered the project.

The site in Calvert County used a caseworker who was the parent of a child with a developmental disability. Consortium sites provided additional parent supports as parent groups or information sessions to meet common needs identified among families. For example, Frederick County organized parent information sessions focused on topics for several families (i.e., behavior management). Montgomery County provided parents the opportunity to join existing parent groups offered through the Jewish Social Services Agency. These approaches by sites ranging from caseworker contact to formal parent groups stress the importance of innovative and varied approaches to increasing supports available to families.

These families also tended to be known to agencies for a very short time (<6 months) prior to entering the Consortium. Research looking at changes in family support networks over the life cycle of children with mental retardation (Suelzle, 1981) found that use of and assistance from personal support networks declined over time as the child aged. Over time parents increasingly sought advice from school personnel. This research supports the belief that social distance and isolation increase over time for families with a disabled child. For the group of families in the Consortium it is not possible to determine whether the social isolation lead to their at risk status but it can be argued that the factors used to describe families in this report create a picture of truly isolated families who have little input or support and who exist more frequently on limited resources.

Child Characteristics

Characteristics of the children served by the Consortium have remained very stable over the project period. The age of the children reflect the full range of ages eligible for the project, birth to 21 years (Table Five). The

mean age of recipients is 8 1/2 years. This is slightly younger than Year One when children were an average of 9 1/2 years but shows no change in the final project year. There are significantly more males than females in the project. The majority of children were white. Ethnic identity of the child is used to describe the family classification. The number of children who received no services prior to entering the Consortium increased over the study period. By Year Three 38% of the children had received no services prior to entry. This figure coupled with the isolation that characterizes the families further highlights their at risk status.

The percentage of recipients attending public school special education programs at entry into the project remained stable. Slightly over one half (56%) of the children were enrolled in public school. An additional 22% were attending a day care/preschool center or another day time program (17%, 5% respectively). One fifth (21%) of the recipients received no day programming at entry. Caseworkers in each site were very active in linking any child who at entry was not in an appropriate daytime program. This usually entailed enrollment in early intervention or home based programs.

Service Needs

At entry into the program each site coordinator identified the child and family factors that put each family at risk of out of home placement. They also indicated the services needed to alleviate the risk of out of home placement.

Thirty-nine percent (39%) of the families had requested out of home placement of their child at the time they entered the program. Therefore in nearly twice as many families the realization that the family was at risk of out of home placement was made by a professional. Significantly fewer children had been evaluated or were on a waiting list for out of home placement (4% and 4% respectively). Why so few families have taken steps to

Table Five

COMPARISON OF CHILD CHARACTERISTICS

FOR THREE PROJECT YEARS

FINAL REPORT

Child Characteristics	Year One	Year Two	Year Three
Age			
<5 years	30%	26%	26%
5-10 years	31%	46%	46%
11-18 years	29%	19%	19%
≥19 years	9%	9%	9%
Sex			
Male	65%	64%	67%
Female	35%	36%	33%
Race			
White	60%	64%	66%
Black	34%	29%	28%
Other	6%	6%	6%
No Prior Services	21%	29%	38%
Daytime Activity			
Public School	59%	55%	56%
None	27%	10%	21%
Preschool/Daycare	*	*	17%
Other	14%	28%	5%

have their child evaluated or placed on a waiting list for out of home care can not be assessed from the data collected.

The major factors contributing to the risk of out of home placement of a child with a developmental disability indicate that over sixty percent of these children have an extreme dependence in self care (67%), and over one half have need for adaptive equipment caregiver 51%. Additional factors further characterize the children as medically ill (45% of the children's caregivers need special training to care for them, 42% have severe medical problems, and 28% display severe behavior problems).

Table Seven summarizes risk factors of the family. Financial problems are a major contributing factor in the risk of out of home placement of these children (72%). Family dynamics and responsibilities are key problems identified by project coordinators as contributing to at risk status. Other family responsibilities or difficulty with siblings were risk factors in over 50% of the families. One third of the families were characterized at risk because of an unsupportive spouse or relatives. Marital problems, divorce or separation characterized nearly one quarter (23%) of the families. Even though these families tended to be two parent households the quality of the relationshp appears to be significantly affected.

Table Eight reflects the services needed by families at entry into the Consortium project to prevent or decrease the risk for out of home placement. Respite care is the service most needed at entry into the Consortium to alleviate the risk of out of nome placement. Need for financial assistance reflects the families financial difficulties stated above as a reason for their need of out of home placement. The need for day programming reflected in Table Eight requires more investigation to clearly identify the reason(s) for the large percentage of children receiving no day program(s). Counseling is the fourth most critical resource needed to alleviate the risk of out of

Table Six

NEEDS OF CHILD CONTRIBUTING TO RISK

OF OUT OF HOME PLACEMENT

ASSESSED AT ENTRY INTO THE CONSORTIUM

FINAL REPORT

Factor	% Families
Extreme dependence in self care	67%
Physical handicaps requiring adaptive equipment	51%
Physical illness/handicaps requiring special training of caregiver	45%
Severe medical problems	42%
Severe behavior problems	28%
Severe emotional problems	9%
Severe community problems	5%
Severely self abusive	6%
Other	15%

Table Seven

NEEDS OF CAREGIVER CONTRIBUTING TO RISK

OF OUT OF HOME PLACEMENT

ASSESSED AT ENTRY INTO THE CONSORTIUM

FINAL REPORT

Factor	% Families
Financial problems	72%
Other family responsibilities/difficulty with siblings	52%
Unsupportive spouse/relatives	32%
Necessary service not available	23%
Divorce, separation or marital problems	23%
Personal adjustment problem	21%
Poor health of caregiver	13%
Caregiver age (too young/old)	10%
Loss of job	6%
Other	23%

Table Eight

ASSESSED RESOURCES NEEDED AT ENTRY INTO
THE CONSORTIUM TO ALLEVIATE RISK OF
OUT OF HOME PLACEMENT
FINAL REPORT

Service	% Families
Respite Care	88%
Financial Assistance	71%
Day Programming	50%
Counseling	47%
Recreation/Social Programming	40%
Behavior Management Program	27%
Adaptive/Social Skill Training	15%
Other	15%

home placement. Two services increased in need between project Years Two and Three. The need for recreation/social programming and the need for behavioral management training increased dramatically. The next chapter will analyze whether the services actually provided to families mirror these two changes in service needs.

The data reported above reflects needs at entry into the program to clearly identify how families needs changed over time in the project. A proxity indicator used was to focus on the services provided. Differences in needs at entry and services provided identified unmet needs. Caseworkers report parents were conservative in the services they requested at entry into the program. They did not see this project as an opportunity to get all they possibly could, rather they identified major service needs only.

Chapter Three

STRESS AND PROGRAM EVALUATION

Questionnaire on Resources and Stress

The Questionnaire on Resources and Stress (QRS) developed by Jean Holyrod was designed to specifically tap the stresses and resources of families with a chronically ill or developmentally disabled family member. This instrument has been used in other studies to document differences in functioning between families with a child with Down's syndrome and families with a child with mental illness. The Consortium has used the QRS to document change in family stress and resources over time.

The most striking finding from analysis of the QRS is the high level of stress these families report. The results of the QRS indicate that their stress is perceived as extensive with many areas affected (i.e., the caregiver's life and the interactions and future of the family), and very intensive in selected areas (i.e., personal burden for the caregiver, physical limitations of the child, financial stability and limits of family experiences).

For families participating in the Consortium in Year one, no change in the QRS scores were noted. this lack of change was thought to be a result of the uncertainty of the continuance of funding for the Consortium in the first year. However, results in Year Two identified decreased stress on two subscales of the QRS. The two areas where stress levels decreased were:

- o Personal burden for the caregiver
- o Physical limitation of the child.

In spite of the decrease on these two scales the families continue to receive scores on the QRS indicating high overall stress.

Results of analysis of the QRS scores in Year Three indicate two trends. Families who have been in the Consortium for three years have in Year Three

continued to score at the stress levels similar to those in Year Two. This means that there was little further decrease in the stress measure by the QRS in these families. It would be naive to think that any project could hope to eliminate all stress these families experience. The results do indicate hope that even minimal amounts of stress can be alleviated in these families and that this can be maintained over time.

The second trend refers to families who have been in the Consortium for two years. The scores of families indicate a similar pattern to that reported previously. Decreases are most significant in the subscales focused on:

- o Personal burden for the caregiver.
- o Physical limitations of the child.

These results should not be seen to imply that the overall stress of these families is low. The families in the Family Support Services Consortium remain highly stressed in several areas. While the findings of decreases in stress do not reach statistical significance, the perception of the recipients is that their lives are better and the Consortium helped not only their child but their family. This perception that their lives are better is significant even though their level of stress based on the QRS remains high. The significance is that a service provision program has been developed that appears to meet the immediate needs to better the lives of these families, and that the caregivers perceive their lives to be better because of the project.

Developmental Status

Two standardized measures to assess developmental status of participants were used by this project. In Year One the Adaptive Behavior Scale (ABS) was used, but was discontinued in Years Two and Three because it proved a time consuming tool to administer (taking on the average 40 minutes to complete) and parents commented that it did not adequately reflect the positive skills

of their child. The Vineland Social Maturity Scale was used in Years Two and Three.

A standardized tool assessing developmental status was included to more clearly describe the serious deficits of this population. Results of the ABS reflected that the majority of the children received scores below the mean on at least three of the five subscales. The Vineland results mirror those of the ABS, depicting children in the project as scoring significantly below the norms on the majority of developmental areas.

HOME Environment

The Home Inventory developed by Caldwell and Bradley was included as a data collection tool to evaluate the quality of the home environments for study participants. There are three forms of the Home Inventory focusing on infancy, preschool years, and elementary school years. This tool was completed primarily by observation during a home visit with open ended questions directed at the caregiver to supplement the observations. Over one third of the children's home environments were assessed to be in the lower quarter of possible scores. The majority (63%) lived in environments where the quality and quantity of stimulation was adequate to excellent. Given the nigh stress levels and isolation of this population, the families are still able to provide at least adequate environments for their children.

Parent Satisfaction Questionnaire

At the end of each of the three project years, families were given a questionnaire to evaluate their reactions to the organization and operation of the Consortium. The instrument used in Years Two and Three was designed to yield information more specific than in Year One. The families were asked to rank order aspects of the Consortium that meant the most to them. The categories highlighted were taken from responses to the open ended questionnaire used in Year One.

The Consortium has received consistently high praise from the families returning the questionnaires. Their responses to "What has the impact of participating in the Consortium been on your family" characterize the Consortium as providing very specific and needed services. The following quotes were written by families as they express what the Consortium has meant to their family.

"It helped us connect with services in this area."

"The Consortium has provided me someone to talk to, it's important to know someone cares."

"Helped to repair a shakey relationship between two parents through occasional overnights away from our responsibilities. It has helped decrease stress and competition between a normal preschool child and a preschool ability disabled child."

"The financial assistance has kept us together and has made an unbearable situation just bearable. We feel loss of assistance would be catastrophic."

"Has been very helpful and extremely supportive."

"Significantly relieved financial strain. The financial help has improved quality of life for our family."

"Tremendous support both financially and emotionally from the superior staff, has enabled us to cope better."

Parents rank ordered five aspects of the Consortium that they considered most important to their family. The list of statements were taken from responses to an open ended question in Year One. As in Year Two, it proved difficult for families to rank order the list as many items seemed equally important to them. Their responses are very consistent with the themes identified by the quotes included above.

While the data obtained from this questionnaire does not lend itself to quantitative summary, this does not decrease the importance of the findings. Parents were able to identify how the program had effected their lives. It was clear from their responses that the program has significantly influenced and improved their lives.

Family Progress Summary

Each site summarized the critical areas where each family made the most progress while participating in the Consortium. In addition families were described by the amount of staff time they require. Finally the coordinators noted if there were services needed by families that the Consortium could not provide. This summary provides a means of describing changes in families over time as well as to understanding better the staff committment required in such a program. Finally, it is necessary to understand what services can not be provided by such a project and why.

After participation in the Consortium the changes families experienced provides another measure used to evaluate the overall impact of the Consortium. Table Nine lists the areas of change families experienced. Each of these factors point to the overwhelming effect of needed services to families.

Table Ten presents the staff time necessary to meet the needs of families in the Consortium. The majority (40%) of families require routine contact with staff two to three times per month. One third of the families require

Table Nine

CHANGES IN FAMILIES ASSESSED DURING

PARTICIPATION IN THE CONSORITUM

FINAL REPORT

Changes	%
Family more stable	40%
More services provided	20%
More accepting of child's disability	13%
Needed Adaptive Equipment provided	11%
Day Programming Obtained	6%
Improved behavior in child	6%
Other	4%

Table Ten

ESTIMATES OF STAFF INTERVENTION TIME

FOR FAMILIES OF THE CONSORTIUM

FINAL REPORT

	Percent
Constant (more than once a week)	7%
Weekly	10%
Routine (2-3 times a month)	40%
Infrequent (one every 4-6 weeks)	33%

less frequent contact with program staff, usually less than once per month. More than one quarter (27%) of the families require contact with staff on a weekly or constant basis (more than once a week). These estimates help provide a better picture of the staff intensive nature of the Consortium. Using the estimates above each month a worker with 20 families would have contact with 3 families at least once a week if not more frequently. They would see an additional 10 families two to three times each month. The remaining seven families on their case load would be seen once every 4 to 6 months. It can be estimated from these figures that a caseworker with 20 families would make 57 home visits a month.

Project coordinators perceived the following major ares of change in families over the time they were involved with the consortium. Families were better able to cope after participation in the Consortium. The home environment was more stable. These are important factors when compared to the risks contributing to the need for out of home placements at entry into the program, when nearly one half of the families were at risk due to a supportive spouse/relative or divorce, separation or marital problems. Families are perceived as more financially stable another improvement from their overwhelming financial need at entry.

The list of changes noted in families is significant in understanding the wide ranging impact this service provision program has had on the participants. The opportunity to provide needed services to families has resulted in remediating many of the serious problems families faced when they entered the project.

OUT OF HOME PLACEMENT

Eight (8) children were placed outside their parents' home in Year Three. A total of 23 children were placed outside their parents' home during the three years of the Consortium project. This represents only 10% of all

children referred to the Consortium who required at least temporary care outside their parents' home. It is necessary to review the reasons the out of home placements were made to clearly evaluate the impact of the Consortium in prevention of unnecessary out of home placement.

Four of the children were removed due to threats of abuse or documented abuse or neglect by the caregivers. In three situations, placements in specialized foster care or other community residences are planned. The fourth child currently lives with relatives in the community. There are no plans to return these four children to their parents home. Only one of these children had been previously placed outside their house.

An additional two children were removed because the primary caregiver became seriously ill. Because of the nature of the illness it is unlikely these two children will return home. One child was accepted into a local alternative residential living unit. The second child while currently in a state residential setting has no plans for alternative placement at this time. This child has been placed outside the home two times previously.

The remaining two children were placed outside their home as a result of their behaivor. One child who lived with his grandparents was placed temporarily in a state residential facility and then transferred to the Kennedy Institute for intensive behavior treatment. This child returned to the grandparents home after discharge from the Kennedy Institute. The second child was placed outside the home for four months in a state residential facility. The child's behavior is very aggressive and destructive.

In summary, over the pilot project, three main reasons characterize the need of out of home placement. The physical safety of the child while in the home is one reason children are removed. In these situations the child is not returned to their home. Placement is sought in the least restrictive community residence available.

The physical health problems of the caregiver has been a significant reason for requesting the child be placed outside the home. These children may be placed only for a short period of time or they may require permanent placement depending on the nature of the illness. The third significant reason for out of home placement is due to the child's behavior. These children have severe behavior problems requiring constant supervision to assure they do not harm themselves or others in the family.

Chapter Four

ANALYSIS OF SERVICES

Service Provision

Each site maintained monthly records of the services provided to each family in the project. These records indentified the purchases service and the caseworker activities and the cost of purchasing each service or providing each activity. The data reported in this section relfect the service and cost information recorded by the monthly family speicific records.

The services provided in Year Three are very similar to those services provided in the two previous years. Table Eleven compares the percentage of families receiving each type of service by project year. All families received some counseling, although the magnitude of this effort was less than in Year One. The amount of counseling provided remained stable from year Two. Respite care remained a significant service in terms of the number of families who receive this service. Respite care was used for consistent hours per week or for extended periods of time. Transportation was a major service need primarily by families on the Eastern Shore and in Calvert County. This service allowed families to keep appointments and to visit their children if hospitalized. This was the only service need that differed by site. Provision of adaptive equipment and medical supplies also remained important services. Adaptive equipment included, wheel chair ramps, bath tub adaptations, wheel chairs, beds and special adaptations to automobiles. Purchase of diapers and feeding supplies represent a major need for this population and showed a major increase in the percentage of all Consortium families who received medical supplies/services at least once. These much needed supplies are not covered by other insurance programs and represent a constant expenditure which families had to purchase out of pocket prior to this program.

Table Eleven

PERCENTAGE DISTRIBUTION OF THE FAMILIES

RECEIVING EACH TYPE OF SERVICE

FINAL REPORT

Type of Service	Year 1	Year 2	Year 3
Family Counseling	100%	100%	100%
Liaison and Monitoring	*	100	100%
Respite Care	27	38	35%
Transportation	14	23	23%
Provision of Adaptive Equipment	13	20	19%
Purchase of Medical Supplies/Services	12	18	26%
Day Care	12	15	9%
Recreation	10	9	11%
Nursing/Personal Care	12	16	13%
Educational Meeting	*	12	14%
Subsidy	6	5	5%
Crisis	3	5	6%
Therapy (OT, PT, HS, BEHAVIOR PSYCH)	16	17	16%
Other	13	12	14%

*not reported in Year One

Liaison and monitoring was necessary to evaluate the impact of services provided to each family and to update the complement of services that were appropriate for each family. In Year One this service was not monitored for each individual family but captured as an administrative function. At the end of Year One the coordinators felt that this service consumed a major amount of their time and therefore could be identified for each family. In Year Three as in Year Two these services performed by the caseworker accounted for a significant amount of the expenditures devoted to each family. It can be assumed that these services will remain critical as well as time consuming as the program continues. The dedication of the caseworkers to this project is evident in the time they spend interfacing with other community agencies.

Finally, attendance at educational meetings persisted as an important caseworker function in Year Three. Site coordinators attended at least one educational meeting for as many as 20 families. The presence of the coordinator at these meetings points to the recognition of the important role the site coordinator plays in the life of the child and his/her family. This service was not recorded in Year One.

The stability over the project period continues and is an extension of the types of services provided. The number of services a family received ranged from one service per family to as many as 12 services in Year Three. In Years One and Two the number of services provided per family ranged from 1 to 10 services and 1 to 9 services respectively. Table Twelve provides a breakdown of the number of services families received. Seventy-seven percent (77%) of the families received four or fewer services. Fifteen percent (15%) of the families received six or more services.

Cost of Services

The cost of services recorded by each site in Year Three reflect only the cost of services directly related to an individual family. Services included

Table Twelve

DISTRIBUTION OF THE NUMBER OF SERVICES
RECEIVED BY A FAMILY IN THE FAMILY
SUPPORT SERVICES CONSORTIUM
FINAL REPORT

Number of # Services	Year Three
≤ 3 services	65%
4	12%
5	8%
6+	15%

Number of services provided ranged from 1 service to 12 services per family

in the determination of cost include all purchased services as well as caseworker time spent in direct contact with the family and in arranging and monitoring needed services. Data on administrative costs, those costs not directly related to an individual family, were not collected in Years Two and Three. The decision for this change in data collection was to devote more time and energy to other data collection and service provision endeavors. An estimate of administrative costs has been made for Year Three based on the difference of the service provision expenses and the total grant allocation.

Two descriptors of cost of services will be identified. First the average cost of services was determined. The average cost of services for the project was computed by summing the cost of all services (purchased and caseworker) provided each month for each family and dividing by the number of families served. Average cost was computed by project site and for the total project. The second cost descriptor identified the range of costs for families (lowest to highest). The range of costs were identified for each site as well as the total project.

The costs of services provided reflect the costs each site furnished on a monthly basis. Cost of caseworker time was computed using the actual hourly wage for each caseworker. By using actual costs incurred by each site the cost data from this report represents the most accurate picture of service costs available. It is important to note that the cost of services reported in this report is a combination of the purchased services and the caseworker services. Examples of purchases services include respite care, purchase of medical supplies and purchase of adaptive equipment. Examples of caseworker services include time spent counseling families, in liaison and monitoring of services, or attendance at educational meetings.

Estimates of the cost of services provided in Year One was $1,350 per family and $1,091.85 per family in Year Two. The average cost of services

provided per family in the final project year was $1,153.42. The range of costs per site extended from $886.34 on the Eastern Shore to $1,560.84 in Baltimore City. Given the wide range of costs by site use of the average project cost must be used with caution. The wide variation in cost per family warrents closer attention and requires that description of project differences be made. Two issues can be summarized in addressing the family cost figures. First, there appears to be an urban/rural difference in assessing the costs of the project in Baltimore City. The composition of families and therefore associated problems inherant in Baltimore City are unlike those in the rest of the state. Poverty and its associated complications account for the increased cost of service provision in this area.

The second issue providing insight into the reasons for the cost differences focuses on project site organization. The Eastern Shore project operates through the existing case management system based on all county health departments on the Shore. The cost of personnel is not absorbed by this project but is paid for through the health departments. Because of the staff intensive nature of this project as has been previously described this accounts for the difference seen in cost of service provision on the Shore.

It would appear that the cost of family support services can be predicted as relatively stable over time therefore, dispelling the myth that families will demand more services over time thus increasing the cost. The project served slightly more children and their families in Year Three than in Year One but at a great reduction in cost. It is unlikely that the average figure will continue to decrease dramatically as the Consortium or Family Support Model is a dynamic process representing entrance crisis needs of families as well as stabilized service needs of families. Families proceed through these steps at varying rates. A program site is currently limited by the available monies and therefore the number of families that can be served. No site

brought more families into the program than they could effectively serve given the family's service needs balanced against available money.

Table Twelve lists the average cost of services per family for each project site in the Consortium. Estimates of administrative costs for Year Three are estimated to remain at approximately $120.00 per family. Administrative costs are any cost not directly attributable to a single family. Including this figure, the total cost of providing services plus program administration costs through this project is $1,270.42 per family. This represents a decrease from Year One where the total cost per family was approximately $2,000. However, differences in total cost varied little between Year Two and Year Three.

Table Thirteen indicates the proportion of families by their total amount of expenditures for services received during Year Two. The service dollars expended per family ranged from slightly under $100.00 to over $4,000.00 per family. There are differences between sites in terms of the range of service dollar expenditures. Baltimore City and Montgomery County have similiar distributions of service expenditures. For these two counties nearly equal numbers of families received services that totaled less than $1,000 and greater than $1,000.00. On the Eastern Shore and in Frederick County one half of all families received services that totaled less than $700.00. It is also shown in Table Thirteen that the distributions for Frederick County and the Eastern Shore were similar. The range of services provided in Calvert County most closely approximates the patterns seen in Frederick County and in the Eastern Shore. To more adequately understand the costs per family it is important to examine the dollar range which encompasses most of the families. This adds further clarification to the average cost of services per family said to be $1,153.42. Defining the dollar range that extends between the lowest figure and a cut off of < $1,500, between 65% and 85% of all families

Table Twelve

AVERAGE COST OF PROVIDING SERVICES PER FAMILY

IN THE FAMILY SUPPORT SERVICES CONSORTIUM

FINAL REPORT

	Service Cost	Estimate of Administrative Cost	Total
Calvert County	$ 1,221.50	$ 120.00	$1,341.50
Eastern Shore	$ 886.34	$ 120.00	$1,006.34
Frederick County	$ 1,020.12	$ 120.00	$1,140.12
Kennedy Institute	$ 1,560.84	$ 120.00	$1,680.84
Montgomery County	$ 1,252.96	$ 120.00	$1,372.96

Project Average for Services Only = $ 1,153.42

Project Average including
Services and Administrative Costs = $1,273.42

in the total project would be included. If the upper range were extended to $2,000, the percentage of families who would be included increases to 65% and 100% depending on the site. The two urban sites are where more families fall outside this last dollar range category. This last classification (lowest to <2,000) is significant in terms of program planning and projected administrative changes as it encompasses.

Cost Effectiveness

An important question to be answered by this project is the degree to which family support intervention services are cost effective. To address this question the annual cost of alternative placements outside the home will be compared to the average cost figure per family identified by this project. The FY 1987 annual costs for out of home placements published by DDA range from $55,480 at Rosewood to $35,770 at Great Oaks. Comparisons of costs of the Consortium to these FY 1987 figures for residential placement shows that a cost effective margin of 44 children and their families can be supported yearly in their home for one yearly residential slot at Rosewood. The comparable yearly figure for Great Oaks is 29 children in home based family support services for a single residential slot. For a child 9 years of age at time of entry into this program, it can be estimated that family support services will cost $16,549 for this child until he/she is 21 years of age. This figure is compared to $465,010 for residential placement in great Oaks until the child turned 21. These costs are conservative because the long range benefit of children remaining with their families can not be truely estimated. Quality of life, and the opportunity for normalized opportunities are additional factors that can not be estimated easily but can be seen to only increase the cost effective margin in favor of the provision of family support services.

Table Thirteen

PERCENTAGE OF FAMILIES CATEGORIZED

BY THE COST OF SERVICE PROVISION

EXPENDITURES BY CONSORTIUM SITE

FINAL REPORT

Dollors Expended

Site	<$100	$100-399	$400-699	$700-999	$1,000-1,499	$1,500-1,999	$2,000-3000	$3,001+
Calvert County	7%	7%	33%	26%	7%	20%	---	---
Eastern Shore	---	16%	42%	11%	16%	---	16%	---
Frederick County	---	19%	31%	19%	13%	6%	13%	---
Baltimore City/County	13%	29%	14%	---	14%	7%	10%	14%
Montgomery County	12%	27%	7%	7%	12%	---	23%	12%

Chapter Five

SUMMARY AND CONCLUSIONS

The three year pilot period of the Maryland Family Support Services Consortium has been able to document clearly the population receiving services, their service needs, and the cost of purchased services and caseworker services.

The original one year grant proposal for this project estimated that 10-15 families per site or a maximum of 75 families would be served in the first year. In the first year of the Consortium 101 families were served, and by the end of Year Two 164 families had received Consortium services. An additional 60 families received services in Year Three. Sites had served between 25 and 82 familis by the end of Year Three.

Stability best describes the characteristics of families receiving services over time. Little change in the sociodemographic characteristics of the children or families were noted. The characteristics of recipients indicate that risk status can not be limited to a specific group. A review of the sociodemographic characteristics of these families identifies two important issues. First, the income of over 60% of families is below $15,000 per year. This is especially striking when compared to the income of the Maryland and the total population of counties served by a Consortium site where 30% and 33% of families respectively had a year income of less than $15,000. This finding would seem to support that presence of a child with a developmental disability represents a drain on the family income. Thus it is not surprising that 72% of the families in the Consortium saw financial problems as a major reason contributing to their child's at risk status.

Secondly, families can be characterized as socially isolated. Only twenty percent (20%) of the families are members of an advocacy group. In addition over half the families receive no assistance from friends, relatives and

agencies. The internal focus of these families has put increasing strain on their ability to cope with the demands of the care of their child with a disability.

Five major findings of the three year pilot period of the Consortium deserve attention.

The average cost of services provided to a family remained fairly stable between Year Two and Three ($1,220.00, $1,273.42 respectively, and significantly lower than the $2,000 average in Year One). Even without consideration of the other significant findings from this project, the cost savings of providing in home services as compared to residential services is substantial. Variation in the cost of services per family is noted by site and reflects as combination of rural vs. urban location and the organizational structure of the site.

Second, only 10% of the children receiving services through the Consortium were placed outside their parents home. The length of placement varied as did the reasons for placement. Three factors seem to describe the reasons children were placed out of their home: 1) physical safety of the child, 2) physical health problems of the caregiver, and 3) behavior of the child. This program model has thus proven that the immediate risk of out of home placement can be decreased if interventions focus on the family unit an work within the families perceived needs.

Third, the Consortium did not establish a waiting list in any of the projects three years. Coordinators firmly believed that no family eligible for Consortium services due to their at risk status should be placed on a waiting list. Because of their critical status the Consortium developed innovative relationships with other community agencies in order to meet the needs of all eligible families referred to this project.

Fourth, stress, an important risk factor effecting a families ability to cope, was reduced after two years in the program. The decreased stress on two important factors personal burden to the caregiver and physical limitations of the child remained lowered after three years in the project. Thus the interventions provided by this project were successful in lowering the stress families perceived. Lowered stress is significant in its implications for correlation with improved functioning of familis.

Last, the Consortium has been able to successfully secure legislated status and transfer the administrative responsibility from the Maryland State Planning Council on Developmental Disabilities to the Developmental Disabilities Administration. Within the projects first year legislation was passed creating a statewide committment to family support services. The next two years represented preparation for transition of the administrative responsibility of this project.

Chapter Six

RECOMMENDATIONS

Based on three years of data collection and daily experience meeting the service needs of families with a child with a developmental disability, the Maryland Family Support Services Consortium offers the following recommendations.

- Undeniably Family Support Services should be expanded statewide in Maryland. The current project serves 13 counties through 5 project site offices. These sites have proven the success of this service delivery model such that future sites will benefit from their experience and expertise.
- Flexibility in service delivery and program operations was a major benefit to the Consortium. Continuation of this flexibility must be seen as a key to assuring the success of existing and future family support projects. Each project site was able to develop its program operations to best meet the needs of families in their area. This flexibility allowed testing of model for program operations utilizing, coordinators who themselves were parents of a developmentally disabled child, cooperative arrangements between two community based providers, and integration with existing case management and service coordination systems.
- This project identified Respite Care as a major need of families at entry into the program. This major need for respite care however, was unable to be met for many families because the services were not available. This project when faced with the unavailability of respite care developed systems on their own. This project should not be developers of services but rather brokers of generic community services. This project has pointed up a grave need to increase the

availability respite care services at the local level. Children with special medical problems require respite care workers who are trained to meet their needs. Respite care for intermittent or for extended periods of time is also needed. The availability of trianed and reliable respite care providers would allow families to receive a truely needed support service.

- o A critical phase in the lives of families with a child with a developmental disability occurs when the child reaches age 18. Educational services continue until persons reach age 21. However, planning for the future needs of these adolescents/young adults should begin before age 21. Transitioning of recipients of family support services into programs providing individual supports clearly represent a major need for future programs. Of what value is the program serving families if no complementary project exists for that same family and their child once he/she turns 21 years of age. Service needs for these persons do not cease but rather their daily activity and residential needs increase. Future programs must address the transitioning period in a manner that decreases the stress of this time on the family with a life time orientation that promotes the healthy and more normalized approach to provision of needed services.
- o Continued documentation of the actual services provided by this program and their costs as well as descriptions of the program recipients is the final recommendation offered. This recommendation is based on the success of the Consortium project to develop a monitoring and documentation system that is manageable and which has proven able to characterize the recipients as well as outcomes of the program.

BIBLIOGRAPHY

Maryland Statistical Abstract, 1986-1987, Maryland Department of Economic and Community Development, Annapolis, Maryland.

1980 Census Profile Population and Housing Characteristics for Maryland Counties, January 1982.

Salkever, David, "Parental Opportunity Costs and Other Economic Costs of Children's Disabling Conditions. Chapter 41, In Chronically Ill Children and Their Families, Hobbs, N., Perrin, J. and Ireys, H. Ed. 1985, Jossey Bass Publishers.

Suelzle, Maryjean, Keenan, Vincent. "Changes in Family Support Networks Over the Life Cycle of Mentally Retarded Persons." American Journal of Mental Deficiency, 1981: 86(3), 267-274.

5884E

APPENDIX A

FAMILY SUPPORT SERVICES CONSORTIUM GRANT
FACT SHEET

FINAL REPORT

224 families are participating in the project

Descriptions of Children

1. The mean age of the children with developmental disabilities in the project is 8.5 years. The children range in age from 4 months to 21 years.

2. Sixty-seven percent (67%) of the children with developmental disabilities in the project are males.

3. Sixty-six percent (66%) of the children with developmental disabilities in the project are white.

4. Eighty percent (80%) of the children are multiply handicapped. Nine percent (9%) of the children in the project have a single diagnosis of mental retardation. Nine percent (9%) of the children in the project have a single diagnosis of cerebral palsy.

5. Fifty-six percent (56%) of the children in the project are in a public school program.

6. Twenty-one percent (21%) of the children are in no day program.

7. Prior to entering the study 38% of the children with developmental disabilities received no services. The majority of children received all of their services through the school system.

Descriptions of Parents and Family Situations

8. Sixty-eight percent (68%) of the parents in the project are married.

9. Nearly one third (30%) of the primary caregivers have not graduated from high school. Slightly more caregivers have a high school diploma than have post high school education (39% and 31% respectively).

10. Prior to entering the study 89% of the families (excluding child with developmental disabilities) received no services (non-medical).

11. Eighty percent (80%) of all families do not belong to an Advocacy or Support Group.

12. Fourteen percent (14%) of the families have an income of less than $5,000. Well over half (62%) of the families have an annual income of $15,000 or less. Twenty-one percent (21%) of the families have an annual income of greater than $25,000.

13. Nearly one half (48%) of all families have Third Party Insurance.

14. Fifty-nine percent (59%) of all project families have no other financial assistance (excluding health insurance).

Description of Service Needs

1. Thirty-nine percent (39%) of the families have requested out of home placement for their child with a developmental disability.

2. Significantly fewer children were evaluated for out of home placement or an a waiting list (4%, 4%, respectively).

3. At entry into the program, an average of three factors relative to the needs of the child noted indicating risk of out of home placement. The most frequently mentioned factors were:
   - o extreme dependence in self care and physical
   - o handicaps requiring adaptive equipment
   - o physical illness/handicaps requiring special training of caregiver

4. At entry into the program an average of three factors relative to the needs of the caregiver were noted that influenced risk of out of home placement. The most frequently mentioned factors were:
   - o financial problems
   - o other family responsibilities or difficulty with siblings
   - o unsupportive spouse/relatives

5. At entry into the program an average of three different types of services were seen as necessary to begin to alleviate need for out of home placement.
   - o respite care
   - o financial assistance
   - o day programing

APPENDIX B

Vignette A

Easter Sundary --1985 a distraught father took his mentally retarded, 5 year old son E., to a state residential center requesting immediate admission. Community respite was unavailable and E.'s father feared he might lose control and physicall injure the boy. E. was admitted on an emergency basis.

This non-verbal child has many aggressive and destructive behaviors, as well as a short attention span and low tolerance for frustration. Caring for E. puts stress on his parent's marriage.

E.'s mother had broken her ankle on the Thursday before Easter and was ordered by her doctor to stay off of her feet. E.'s father then became the principle caretaker. Attempting to manage his disruptive son and care for his wife at the same time, E.'s father became distressed. When E. broke the family's color television, his father sought residential placement.

Following casemanagement services, E. returned home within three days of his admission. Throughout the next 3 months, homemaker and respite services were provided. A behavior program was begun, including parenting classes for E.'s mother, but the lack of family cooperation made the program difficult to institute.

During August 1985, E. was readmitted to the residential center for a 3 month long behavioral management program. During his stay, E.'s mother worked with the behavioral program staff. Upon discharge, community support services resumed with frequent respite care provided to the family. The behavior program was adapted to the home and school settings, with frequent follow-up by the behavioral psychologist. E. is also followed by the county's mental health clinic.

Arrangements have been made for E. to attend a recreational day camp during the summer months. Continuing case management services are assisting this family to stay together.

Vignette B

S., a mildly retarded 15 year old black male with Cerebral Palsy, is the son of a then unmarried 15 year old mother and a 19 year old father. S. lived with his maternal grandparents and mother for most of his life and then moved to another home with his mother and stepfather upon their marriage in 1983.

S. communicates well and expresses his needs. Although able to feed himself, S. otherwise requires total physical care. The difficulty of lifting him increases as he grows. Three orthopedic surgeries have released contractures of his lower limbs.

Early in 1984, S.'s mother requested that he be placed outside the home. She sought full time employment and wanted to be relieved from her son's care. Aware of his mother's request, S. became withdrawn and depressed. While the family sought counselling, a personal care attendant began daily 2-3 hour home visits. Frequent respite services provided S.'s mother and stepfather relief from his care.

When S.'s mother became pregnant in September of 1984, his withdrawal and depression increased. Psychiatric intervention with ongoing counselling was necessary. S. responded to the therapy and became interested in the forthcoming birth.

He was placed in respite care at the time of his sibling's birth and remained there for three months while his mother regained her strength. Close relationships were maintained as his casemanager and family members visisted frequently.

Upon his return hom, arrangements were again made for daily attendant care. Frequent respite care on weekends is provided through the Family Support Program.

This summer, S. will attend a two week residential camp and a four week recreational day camp. It is anticipated that these continued support systems will help maintain S. at home.

Vignette C

X., a severely and profoundly retarded child with cerebral palsy and seizure disorders requires total care. This is provided by her sister, who is the principle caretaker for three other people residing in the family's small home.

Stressed by this overwhelming responsibility, X.'s sister became depressed and often remained in bed, rather than facing her daily problems. The school social worker's referral was prompted by the sister's depression and concern about the family's living conditions.

Program intervention included respite care that helped X. with feeding, bathing and dressing each school day. This allowed the sister to attend self-improvement workshops and become active in her church, participating in a program for training counselors. She also developed a small part-time business that provides an independent income.

An assessment by our consultant nurse determined a need for comprehensive medical care. The program arranges appointments, acts as liaison with physicians, and regularly brings in a physical therapist. The destructive effects of X.'s anti-convulsive medication necessitated dental care. A dentist was located who works with the disabled and a flexibile payment plan was agreed upon.

The grant also purchased disposable diapers. Prior to this, rags were used and washed out, creating unsanitatry conditions and adding greatly to the family's laundry load.

Because this individual passed the age limit criteria allowed for involvement with the Project, this case was recently closed. In lien of an individual support services program to refer X. and her family to, this project attempted to creat a continuation of services in as many areas of concern as feasible, while she waits for placement in a day program. Hopefully, these resources, coupled with her family' desire to keep her at home, will prove sufficient until an adequate program becomes available.

Vegnette D

This family's two handicapped children require 2-3 hour long tube feedings. Four and six years old, the children suffer with an undiagnosed degenerative disease. The mother is homebound due to the overwhelming needs of these children. The father works from 4 to 12.

At the time of referral, feeding supplies alone case $500 per month. The family is barely over scale for Medical Assistance.

Two years prior to entering the program, the family discovered that B., the younger son, had the same degenerative disease as his brother, A. This, along with overwhelming medical bills, forced the family to place A. outside the home for a year. When A. returned home, the family's financial situation again rapidly deteriorated.

This project provides the family with a trained respite care worker who can give appropriate care to both boys. In addition, it helps to defray the costs of feeding supplies and diapers. (At the project's end, feeding supplies had risen to over $600 per month.) A. now receives home teaching through the city city school system.